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**Diabulima Through the Lens of Social Media: A Qualitative Review and Analysis of Online Blogs of People with Type 1 Diabetes Mellitus and Eating Disorders**

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**Diabulima Through the Lens of Social Media: A Qualitative Review and Analysis of Online Blogs of People with Type 1 Diabetes Mellitus and Eating Disorders**

Running title: Diabulima Through the Lens of Online Blogs

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**Novelty statement**

**‘What is already known?’**

- People with type 1 diabetes who also have an eating disorder are difficult to treat, because the underlying factors are not well understood.

**‘What does this study add?’**

- Multiple factors that trigger and maintain intentional insulin restriction have been identified in this thematic analysis.
- Taking small steps at a time is a key recovery strategy described by people with “diabulimia”.

**‘What are the clinical implications of this study?’**

- Triggers for insulin omission behaviour as well as recovery strategies identified here may contribute to the future development of a clinical intervention for people with type 1 diabetes and an eating disorder.

## AIMS

Diabulimia is a term used by people with type 1 diabetes to describe their eating disorder that is characterised by deliberate restriction of insulin to control weight. Diabulimia is associated with high morbidity and mortality, but very little is known about the experience of living with diabulimia, because these people are vulnerable and hard to reach.

## METHODS

We conducted a structured qualitative review of online blogs published between 2012 and 2017 authored by people who report having type 1 diabetes and an eating disorder or diabulimia. The subsequent thematic analysis followed a six-phased process and was conducted by two independent researchers.

## RESULTS

From 147,000 search results, 11 blogs (304 posts) matched criteria for further analyses. Three key themes and 18 subthemes emerged: 1) Bloggers described different aspects of their relationship with insulin, including motives for omitting insulin, secrecy of insulin omission and perception of control; 2) Bloggers' experiences of diabetes complications, diabetes ketoacidosis in particular, were described, as well as their worries about future complications; 3) Strategies for recovery and triggers for relapse, which involved diabetes self-management and setting up a support system.

## CONCLUSIONS

Qualitative analyses of blogs authored by people with type 1 diabetes and an eating disorder or diabulimia have identified high levels of diabetes distress and provided insight into different motives of insulin omission and strategies for recovery. Considering the limited evidence for effective interventions, these findings may help the development of complex interventions to improve biomedical and psychological outcomes in this group.

**INTRODUCTION**

The diagnosis of type 1 diabetes mellitus is a life event, and living with it involves multiple significant practical challenges. Self-managing type 1 diabetes entails frequent checking of blood glucose, calculating carbohydrate content of meals, considering the effects of exercise and self-injecting insulin in adjusted doses. These burdens and role transitions are predisposing factors for mental disorders such as depression, eating disorders and for diabetes specific distress, such as fears of insulin related weight gain and fear of acute and chronic diabetes complications (1,2).

Eating disorders are amongst the most common mental comorbidities of type 1 diabetes. Eating disorder prevalence is doubled in young people with type 1 diabetes compared to the background population (3). These include, but are not limited to, bulimia nervosa, binge eating disorder and anorexia nervosa (4).

Diabulimia is not currently a diagnosis separate from generic eating disorders in standard psychiatric classifications (The International Classification of Diseases, Tenth Revision; ICD-10 and The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-5). Diabulimia is a term often used by people with diabetes to refer to their condition because it is only possible in type 1 diabetes. Diabulimia is characterised by the fear that insulin causes weight gain and by the deliberate restriction of insulin to control weight. Insulin restriction is associated with a three-fold increased risk of mortality compared to people with type 1 diabetes who do not insulin restrict (5). Mortality is secondary to acceleration of microvascular and macrovascular complications (6,7) and to acute complications such as diabetic ketoacidosis or severe hypoglycaemia (8,9). There is currently no effective intervention that improves diabetes control and mental health in people with type 1 diabetes and eating disorder (10).

A greater understanding of the thoughts, beliefs and experiences associated with

intentional insulin omission, eating disorder behaviour, and recovery from eating disorder in people with type 1 diabetes and eating disorder is needed to inform the development of effective interventions.

Blogs are personal diary-type posts published online by an individual. Structured analyses of blogs represent a novel method of qualitative research as they give access to a range of ready-made narratives (11-13).

The aim of this study was to perform a qualitative review of online blogs authored by people self-identifying as having type 1 diabetes and an eating disorder, or diabulimia.

## PARTICIPANTS AND METHODS

### Data Collection

We applied methods previously developed for a structured approach for qualitative reviewing of blogs (11-13). Data for thematic analysis consisted of written content from personal online blogs, obtained through the search engine Google. Data collection began in February 2017 by identifying blog sites from the search terms 'type 1 diabetes' AND 'eating disorder' OR 'bulimia' OR 'anorexia' OR 'binge eating' OR 'diabulimia' AND 'blog'. The results were ranked in order from the most to least relevant, based on keyword occurrence. Each of the websites were independently reviewed by two researchers (ES and MS) to assess if they met the inclusion criteria: content was located on a publicly accessible and personal blog site or forum; the blog was published within the previous five year period; the author self-identified as having type 1 diabetes and an eating disorder (including the term diabulimia); the blog was written in English.

Blogs were excluded if the author mentioned other existing chronic conditions unrelated to their diabetes or eating disorder (e.g. cancer, neurological disease). We excluded blogs authored by third parties (medical professionals, care givers, journalists) and blogs

published on sites maintained by service providers. Links to related blogs that were found within blogs were also included if they met the criteria (n=2).

All posts within each blog were fed into the primary analysis. Both analysts read these posts in full length and identified those that were related to personal experience of either diabetes or eating disorder or diabulimia. These were included into the next step for the coding process of the thematic analysis. In contrast to a semi-structured interview study or a focus group study with a clearly defined interview or topic guide, blogs also included posts referring to some every day life topics that were not related to our research question and posts citing or linking to other sources (newspaper and research articles) rather than personal experience. We excluded posts that were not related to the research topic. For each blog a maximum of 15 posts (the most recent) were included in the analyses.

Informed consent was not required as this research focuses on the blog rather than the blogger and only public blogs were used (14,15). All data has been password protected and blog authors have been given a non-identifiable ID.

**Data analysis**

A thematic analysis approach was adopted, which is a qualitative method for identifying, analysing and reporting patterns within a dataset. We applied Braun & Clarke’s six-phased framework of analysis (16). Firstly, authors familiarised themselves with the data and read all blog posts in full length (primary analysis). Blog posts related to the research topic were then input into Nvivo® software for data management where initial codes were created by two researchers independently and then jointly. Both worked on the coding at each stage of the analysis. The blog transcripts were read several times and initial codes were generated before being collated into potential themes. A blog extract could be un-coded, coded once or coded multiple times. Researchers worked independently in the identification of themes and several

face-to-face meetings took place to discuss emerging themes. Both analysts agreed that data saturation had been reached (i.e. no new codes could be created). Themes and subthemes were agreed through a collaborative process between the two authors (one diabetologist, one psychologist) conducting the analysis and discussed within the larger multidisciplinary group of co-authors (psychiatrists, psychologists, people living with diabetes). This multidisciplinary approach was taken to allow a broad approach to the qualitative analysis due to the different professional backgrounds and experiences. Themes were reviewed and refined, subthemes consolidated or merged into existing themes, descriptive labels altered to best reflect the subject matter or deleted if deemed irrelevant. Lastly, theme names were defined which ensured blog content was fully captured and a report produced.

## RESULTS

### Systematic search

Figure 1 is a flowchart illustrating how blogs were systematically reviewed. The search term produced 147,000 results. The first 100 results produced 11 relevant blogs (304 posts). We had demographic information for seven bloggers. The age range was between 25 and 34 years. All bloggers identified as female. Bloggers came from the United Kingdom (n=4), United States (n=4), or did not provide information on their location (n=3). The number of posts per blog varied between three and 124. 10 of the 11 bloggers referred to their condition as “diabulimia”. Bloggers also mentioned “anorexia”, “eating disorder” and “type 1 diabetes with an eating disorder”. One blogger talks about professionals referring to her as a “SEED patient” (severe and enduring eating disorder).

### Thematic analysis



Three main themes emerged: bloggers’ relationship with insulin; experience of diabetes complications and; strategies for recovery and triggers for relapse. The themes and subthemes are presented in Figure 2.

**Relationship with insulin**

The majority of bloggers reflected on their use (and omission) of insulin in an emotionally charged and multi-layered way, as if they were reflecting on a relationship that is difficult and complex. Therefore this theme was labelled as ‘relationship with insulin’. This theme was rich and multi-facetted, because there was a broad spectrum of perceptions, thinking patterns, emotions and behaviours related to insulin administration and insulin omission, respectively. For example, a wide variety of factors that trigger and maintain the deliberate manipulation of insulin, which is the key behaviour driving diabulimia, was described.

Bloggers’ perceptions of the influence of insulin on body weight was a subtheme that occurred frequently in the blogs. They reported that giving the correct dose of insulin immediately led to sudden weight gain. Bloggers expressed their worry and fear of gaining weight as a consequence of injecting insulin. Some describe that they began to associate insulin with fat. They also described the struggle they had when reintroducing insulin, because it was associated with weight gain.

*The weight gain was psychologically crippling. (ID 113)*  
*My weight ballooned and I gained about two stone - the teasing at school began and thus I began to associate insulin with fat. (ID 111)*

Experimenting with insulin was driven by a broad spectrum of triggers that ranged from fear of gaining weight, to a perception of control and intentional manipulation. One blogger

1  
2  
3 compared manipulating insulin with a game. Several bloggers appeared to have gone through  
4  
5 a process of conscious decision-making, almost a quasi-experimental approach to their own  
6  
7 body, when they first started intentionally omitting insulin.  
8

9  
10 *At sixteen years old, feeling the pressures of being around other girls in sixth form, I first*  
11  
12 *made the conscious decision to cut out my insulin in order to lose weight. (ID 111)*

13  
14 *This was when the 'experiment' started. I decided to experiment with my insulin; taking less*  
15  
16 *and less, until I was taking none at all. (ID 113)*  
17

18  
19  
20 Some bloggers attributed gambling features to their pattern of omitting insulin. Others  
21  
22 described how features of addiction (in their own words) became associated with insulin  
23  
24 omission.  
25

26  
27 *For years I played the game of omission, only intermittently having spurts of inspiration to*  
28  
29 *become 'a better diabetic'. (ID 121)*

30  
31 *[...] alike to a stupor I could only imagine would compare to what heroin addicts find so*  
32  
33 *addictive. (ID 113)*  
34

35  
36  
37 The secrecy of insulin omission for weight loss, as well as a perception of control over body  
38  
39 weight by omitting insulin, were described and associated with a sense of empowerment.  
40

41  
42 *With the secret eating and insulin omission, I began to lose weight. (ID 111)*

43  
44 *I felt as if it was my secret tool that nobody knew about and nobody else could do. (ID 111)*  
45  
46  
47  
48

49 The chronicity and cyclical nature of insulin omission behaviour was a theme that emerged  
50  
51 from four blogs. The initial experimental approach gradually converted to chronic intentional  
52  
53 omission or restriction behaviour with the intention to manipulate body weight. Other  
54  
55 common cognitions included the ambivalence of fearing weight gain but at the same time  
56  
57  
58  
59  
60

also wanting good diabetes control. These cognitions became discordant when the blogger had a binge as a response to negative thoughts and feelings, but also wanted to be a “good diabetic” by giving the correct amount of insulin that matched carbohydrate intake of the binge, in order to not worsen diabetes control.

*I would omit my insulin to get the extra few pounds off and then would stop. Anybody with diabetes and an eating disorder will know that this is never the case. Once becomes twice, twice becomes three times and so the cycle continues.* (ID 111)

*I thought if I couldn't stop the binging, I could at least stop the weight gain. So anytime I binged, I wouldn't take insulin.* (ID 119a)

**Experience of diabetes complications**

Almost all blogs described the experience of acute and/or chronic diabetes complications. The language used by the bloggers was full of medical terms to describe their acute complications leading to hospital admission, the chronic complications they experience and how they cope with these in their daily lives. In spite of the medical terminology they use, this is a theme where they link strong emotions to their experience, describe how they cope and their thoughts about their future health.

Diabetes ketoacidosis (DKA) was the most described diabetes complication in the blogs. It was common for most bloggers to describe hospital care for the treatment of DKA. Some blogs read like rational and distanced descriptions of the DKA experience. The bloggers also described the opposite experience of an excessive insulin dose leading to severe hypoglycaemia, which in turn triggered compensatory overeating behaviours.

*I was in such severe DKA that I needed to be in their ICU for the first 4 days.* (ID 112a)

1  
2  
3 *I must have overshot with the insulin, sent myself crashing through the roof and the floor. (ID*  
4  
5 *115)*

6  
7  
8  
9 Although DKA and severe hypoglycaemia are medically classified as acute diabetes  
10 complications, there were descriptions of frequent and repetitive episodes of acute diabetes  
11 complications in the context of diabulimia, which represented a chronic illness type burden to  
12 the participants. Some reported how they continued their daily life whilst experiencing  
13 clinical symptoms of acute diabetes complications, suggesting they had gloomily accepted  
14 DKA and severe hypoglycaemia as part of their life and had adjusted to it.  
15

16  
17  
18 *[...] Was walking to and from work every day in severe ketoacidosis but I kept at it. (ID*  
19  
20 *111) Concentrating at school was extremely difficult. My eyes would blur due to the raised*  
21  
22 *blood sugar levels, making simply reading the set work a challenge. (ID 113)*  
23  
24  
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26  
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29  
30

31 Diabetes long-term complications impacting on the bloggers' everyday life was a recurrent  
32 theme of most blogs; the reports vary depending on the complications suffered by the  
33 individual. For example, some bloggers describe the symptoms of severe neuropathy causing  
34 pain and loss of autonomic function. The impact of diabetes late complications on their  
35 quality of life is conveyed through more emotive comments, some of which are gloomy and  
36 cynical in nature.  
37  
38  
39  
40  
41  
42  
43

44 *I have been told I need a permanent catheter [...] I will have to live the rest of my life with a*  
45  
46 *piss bag strapped to my leg. (ID 110)*  
47

48 *Thanks to the decade of damage I did to my body, I am now also the proud recipient of*  
49  
50 *peripheral neuropathy, vasovagal syncope, and gastroparesis – which caused three ulcers*  
51  
52 *and cyclical vomiting syndrome. (ID 112a)*  
53  
54  
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60

Fears of future diabetes complications are drastically and explicitly described by the bloggers, including their own and future family’s wellbeing. They describe the threat their condition imposes to their physical integrity and their life.

*Diabetes always complicates things. It’s even possible the pregnancy could go horribly wrong. I could die; the baby could die; the baby could have serious developmental issues.*

(ID 119b)

*I know that I wanted a family one day, with my limbs, eyes, heart, kidneys, and myself intact.*

(ID 117a)

Some bloggers described their fear of future complications from a personal and insightful perspective, acknowledging the self-harming component of insulin omission behaviour, ranging from not caring for one’s health to the extreme of referring to insulin restriction as “slow suicide”.

*I put my body in harm out of pure desperation to lose weight. I soon realized how damaging and harmful this was. I was doing no justice to myself.* (ID 117b)

*I know in my heart that the worst consequence from this slow suicide was the deceit.* (ID 113)

**Strategies for recovery and triggers for relapse**

All blogs discussed recovery and across all blogs this theme was characterised by a strong willingness to share one’s individual experience of recovery in order to help others. These included describing rational strategies for recovery that involve emotional and diabetes self-management strategies. Some blogs discussed new relationships appearing to be instrumental in recovery. Feelings of empowerment, optimism and hopefulness were often mentioned in the context with the recovery process.

*I’m empowered that I can control this disease and not let it control me.* (ID 117b)

1  
2  
3 *I am happy to say that over the past few years, I have taken my chance at recovery, and I*  
4 *have run with it. (ID 121)*  
5  
6  
7  
8

9 Many of the recovery strategies described by bloggers were focussed on experimenting with  
10 structured dietary approaches and prioritising healthy life style over weight loss. Some tried  
11 to develop strategies to help manage weight and to be able to reduce insulin doses for meals.  
12 Others were instead focused on a relaxed attitude towards body weight and prioritising being  
13 healthy over being thin.  
14

15  
16 *These carbs provide me with the nutrients that I need. They also help sustain my blood sugar*  
17 *throughout the day. (ID 117b)*  
18  
19

20 *There's no undereating. There's no starving myself or throwing up after a binge. This has*  
21 *nothing to do with my body image. It has to do with my health and how I feel about myself.*  
22 *(ID 119c)*  
23  
24  
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31  
32  
33 Improving diabetes management and recovering by taking small steps at a time and being  
34 patient was described as a key strategy. Even seemingly small changes made a difference on  
35 the route to recovery.  
36

37  
38 *I'm just concentrating on keeping my blood sugar levels stable, eating right, and staying*  
39 *active. The results will come with time. (ID 117b)*  
40  
41  
42

43 *You don't need to make the decision to change the rest of your life right now. Recovery is all*  
44 *about micro-decisions - an infinite list of small choices you make every day. ID 112b*  
45  
46  
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49

50 Resources and triggers for recovery included new relationships and new roles in life (e.g. a  
51 new romantic relationship or motherhood), but also the experience of life threatening  
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1  
2  
3 complications. Surviving a severe DKA episode was described as a wake-up call for recovery  
4  
5 by one blogger.

6  
7 *I'd like to take a moment to thank my boyfriend. I thank you dearly, for looking after me*  
8  
9 *when I could not look after myself [...]* (ID 113)

10  
11 *Becoming a mother was what helped me see my life in a different perspective. That there is a*  
12  
13 *reason that I'm here.* (ID 117a)

14  
15 *[...]I had to share a room with 3 other women once I was released into a regular ward. They*  
16  
17 *all died, and I realized that by some miracle I had been given a second chance.* (ID 112a)

18  
19  
20  
21  
22 Bloggers highlight the importance of surrounding themselves with a support system in  
23  
24 recovery, which includes health care professionals as well as friends and family.

25  
26 *The first and most important step is to set up a treatment team.* (ID 112b)

27  
28 *A good tactic to evade this trap of secrecy is to choose at least one friend or family member*  
29  
30 *that you trust - someone that you make a pact with - no lies.* (ID 112b)

31  
32  
33  
34  
35 Bloggers' intentions to help others have been an important part of recovery. Previous peer  
36  
37 support motivates some bloggers to continue helping others in order to reciprocate the help  
38  
39 they received.

40  
41 *They are women who, not only help encourage me to live my best life in harmony with my*  
42  
43 *diabetes, but also provide me with valuable wisdom, guidance, and most importantly, a*  
44  
45 *supportive shoulder to lean on when needed.* (ID 121)

46  
47  
48 *To help others, to educate, to inspire, to empower, and show compassion.* (ID 117a)

49  
50  
51  
52 Triggers for relapse, such as peer pressure for thinness and stressful life events were  
53  
54 commonly described.  
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56  
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1  
2  
3 *Even friends who don't mean to trigger are suddenly opting for skinny lattes. Comments*  
4  
5 *overheard all around 'oh I have to get back on the treadmill!'. (ID 114b)*  
6

7 *When I moved to a new city a year after my diagnosis, the troubling signs returned. (ID 119a)*  
8  
9  
10

## 11 12 13 **DISCUSSION**

14  
15 This structured qualitative review of internet blogs written by people with type 1 diabetes and  
16  
17 an eating disorder, or diabulima, used thematic analysis of blog content to get insight into  
18  
19 experiences, thoughts and feelings of this group of people.  
20  
21

22 Although wider search terms describing various subsets of eating disorders were used,  
23  
24 the majority of blog authors used the term “diabulimia” to refer to their condition, which  
25  
26 confirms the term has face validity in the patient community (17). The 11 diabulimia blogs  
27  
28 were all authored by women in their 20s and 30s, which parallels the observations of female  
29  
30 gender bias in eating disorders (18). Research suggests males are less likely to come forward  
31  
32 due to increased stigma and traditional male gender roles (19). Typically, the age of onset of  
33  
34 an eating disorder is mid to late adolescence, either soon after the onset of type 1 diabetes or  
35  
36 onset of puberty (5,20,21). One could speculate that these adult bloggers are further along in  
37  
38 their recovery and therefore able to talk (blog) about their strategies, resources and triggers.  
39  
40

41 The subsequent thematic analysis identified three main themes: bloggers' relationship  
42  
43 with insulin; experience of medical complications and; strategies for recovery and triggers for  
44  
45 relapse. Interestingly, the relationship with insulin theme gave deep insight into a multi-  
46  
47 faceted problem with a wide variety of factors that trigger and maintain the deliberate  
48  
49 manipulation of insulin, which is the key behaviour driving diabulimia.  
50  
51

52 The pattern of fear of weight gain leading to insulin omission, as well as insulin  
53  
54 overdose following binge eating episodes are patterns which have been previously described  
55  
56  
57  
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59  
60



(22), but the deeper seated motives behind the insulin manipulation that bloggers described such as the “thrill”, “addictive”, “experimental” or “secretive” aspects of insulin omission were novel observations. Preliminary evidence has found highly processed foods share pharmacokinetic properties with addictive drugs (23). Additionally, animal models of bulimia suggest bingeing on food releases dopamine (24) similar to human addiction processes. The acknowledgement of insulin omission as self-harming behaviour expressed in the blogs highlights the inherent ambivalence of these behaviours.

It is not surprising that blogs discussed hospitalisation following DKA, as insulin omission due to diabulimia increases DKA risk significantly (25). Although DKA and severe hypoglycaemia are acute diabetes complications, we made the observation that bloggers with diabulimia experience repeated and cyclical patterns of these complications. Their description of how they adjust to living with recurrent DKA and severe hypoglycaemia contradicts the medical categorisation as acute complication. In the context of type 1 diabetes with an eating disorder, recurrent diabetes acute complications are being experienced like a chronic illness burden rather than as an acute event, which is a novel observation in this group. Interestingly, the language in which the bloggers reported their acute and late complications of their diabetes was medicalised. This may be a result of living with diabetes for a long time and having many interactions with health care professionals where people with diabetes adopt their use of language when talking about their condition (26).

Previous research suggests that people with diabetes and an eating disorder may have unhelpful beliefs about insulin and lack coping strategies to manage recovery (21,27,28). In contrast, we found that some of these bloggers were very insightful about the consequences of insulin omission and the self-harming nature of the eating disorder behaviour. Their accounts of the burden of having severe diabetes late complications (including the fear of

1  
2  
3 experiencing late complications in the future) indicate that most of the bloggers are fully  
4 aware of the consequences of their insulin restriction. This observation is confirmed by the  
5 self-reflection of some bloggers who, from a personal and insightful perspective, refer to their  
6 behaviour as self-harming or even “slow suicide”. Some were even able to share their  
7 strategies, resources and triggers for recovery, which often included helping others.  
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13  
14  
15 We found a mixture of healthy and unhealthy attitudes towards food in their approaches to  
16 recovery. Some bloggers recognised the need for carbohydrates whereas others decided to  
17 use restrictive diets. The concept of approaching the recovery process in small steps was a  
18 common subtheme with various aspects of recovery, including insulin injections, accepting  
19 body shape and keeping blood glucose stable. Some blogs discussed peer pressure and social  
20 relationships with new relationships appearing to be instrumental in recovery.  
21  
22  
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### 31 **Limitations**

32  
33 Blogs are written for many reasons (29) and are not free from self-presentational bias, but  
34 there is also evidence that blogs can be considered trustworthy (30) and rich data (13). It is  
35 difficult to collect participant demographic data for blogs as they allow complete anonymity.  
36  
37 Another limitation of blogs is that they do not capture the views of all individuals suffering  
38 with type 1 diabetes and an eating disorder (i.e. the majority who do not blog). As with all  
39 qualitative studies, researchers have an influence on the interpretation of their findings (13).  
40  
41 We hoped to reduce this bias by taking a multidisciplinary approach.  
42  
43  
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49

50 Qualitative analyses of blogs authored by people with type 1 diabetes and an eating disorder  
51 or diabulimia have identified high levels of diabetes distress and provided insight into  
52 different motives of insulin omission and strategies for recovery. Considering the limited  
53  
54  
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evidence for effective interventions, these findings may help the development of complex interventions to improve biomedical and psychological outcomes in this group.

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**Conflicts of interest**

None declared.

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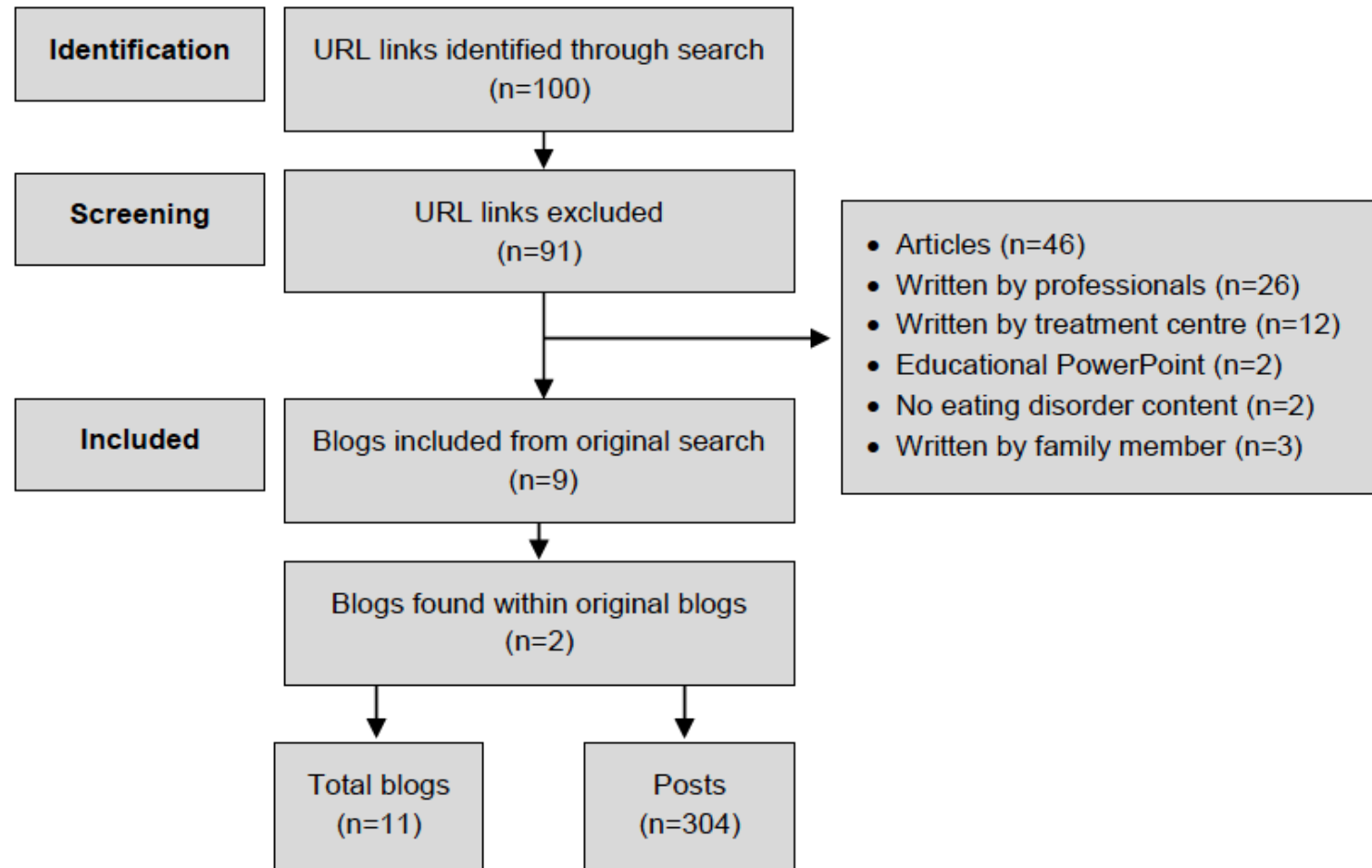
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**Figures**

Figure 1. Flowchart illustrating how blogs were systematically reviewed.

Figure 2. Thematic map illustrating themes and subthemes.

Figure 1. Flowchart illustrating how blogs were systematically reviewed





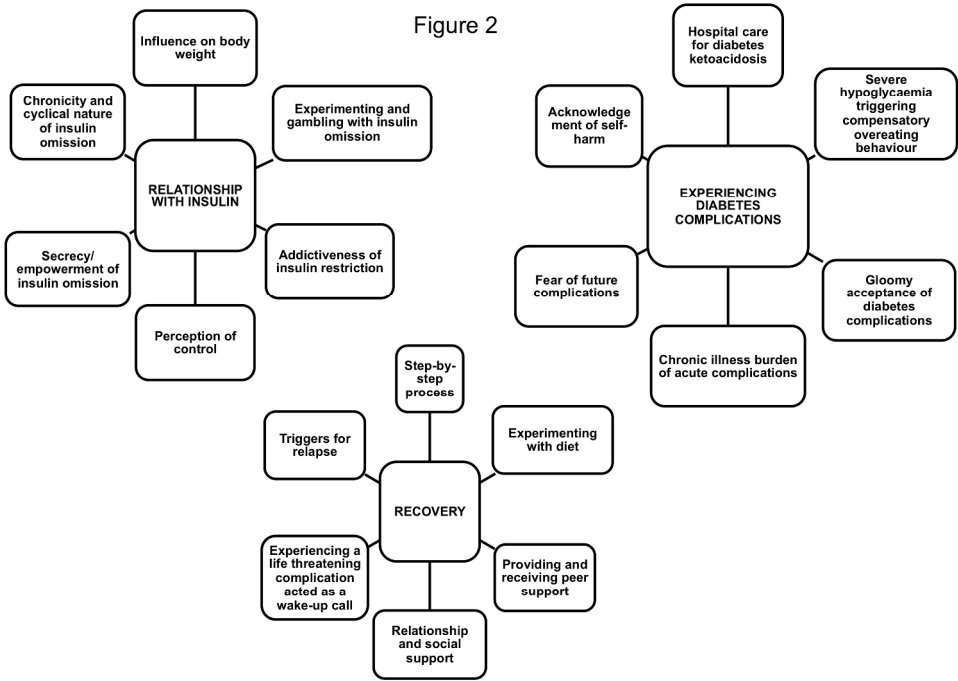


Figure 2. Thematic map illustrating themes and subthemes

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